STATE OF VERMONT

HUMAN SERVICES BOARD

In re	)	Fair Hearing No. 10,988 & 11,088
	)	
Appeal of	)	

INTRODUCTION

The petitioners appeal the decisions by the Department of Social Welfare denying their applications for Disabled Child Home Care (DCHC) benefits under Medicaid. The issue is whether the petitioners require a level of care usually provided in a hospital or nursing facility.

FINDINGS OF FACT

The petitioners are sisters, ages sixteen and eleven, who both suffer from cystic fibrosis, an inherited progressive disease of the respiratory system. Their present conditions are markedly similar. Although they live at home and attend school, they are prone to periodic lung infections that require intense treatment with antibiotics.

The petitioners' mother, who is an LPN, has learned to provide the petitioners with daily treatment and care. She has also learned to provide the petitioners with more acute care that, when necessary, would normally require the petitioners to be hospitalized.

The petitioners' longstanding treating physician, a pulmonary specialist, provided the following overview of the petitioners' conditions and treatment histories:

> [Petitioner] is in my care for management of her cystic fibrosis. Her disease has resulted in recurring lung

> infections which severely limit her ability to attend school and participate in normal childhood activities. Treatment of the infections must be carried out on a daily basis and involve respiratory therapy sessions as well as several doses of antibiotic each day. In spite of these efforts, infections occur which require administration of intravenous antibiotics and application of vigorous chest physiotherapy four times daily for periods of 2-3 weeks. These episodes are occurring every 2 to 4 months.
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> Prior to 1988, these episodes were treated in the hospital, with attendant high costs and long periods of absence from home and community. In that year, [petitioner's mother] acquired the skills to administer intravenous antibiotics at home. Since that time, most of the episodes have been treated at home, and [petitioner] has been able to continue to attend school and to maintain her peer contacts in spite of her recurring episodes of illness.
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> This pattern of care has resulted in significant savings in health care costs by the system, but it has increased the costs and the energy investment required of the parents. It has been shown to be effective and also appropriate for [petitioner[to receive this care at home even though it is care with the level of complexity and intensity usually only provided in the hospital.

The petitioners' pediatrician has also provided a description of their conditions and the care they require. It is as follows:

> [Petitioner] is a 16 (11) year old girl who has been a patient of mine for the past eight years, however, I have only provided the majority of her care for the past 3 1/2 years. She has cystic fibrosis which is an inherited disorder that affects many different organs of the body, most notably the lungs and the pancreas. Increased mucus production in the lungs leads to recurrent pneumonia's and progressive lung disease and destruction of normal lung tissue. The pancreatic disease results in a decrease in the flow of digestive enzymes to the intestine and therefore failure to absorb certain foods, causing many children to fail to thrive. The disabilities of cystic fibrosis result primarily from the increasing lung disease.
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> [Petitioner] requires daily treatment and care. When "well" she takes two oral antibiotics, Caftan and Bacterium, twice a day. She also takes oral

prednisone, an antiinflammatory agent, once every other day. [Petitioner] also receives chest physiotherapy (from her mother) twice daily which takes approximately 15 minutes each time. This includes an aerosolized treatment with Albuterol (a bronchodilator) and Gentamicin (an antibiotic), she then gets chest percussion using a direction stroking percussor. She also takes Pancreas with every meal including snacks to aid in her digestion. The number of Pancreas tablets varies according to the size of her meal.

[Petitioner] is highly susceptible to repeated lung infections because of the increased viscosity of the mucus secreted within her lungs. With an exacerbation of her disease, which is manifested by an increase in cough, decrease in appetite and a decrease in her exercise tolerance, a sputum culture is obtained to see what organisms are causing the problems. Initially her oral antibiotics are changed to Dicloxicillin and Cloramphenicol which she receives four times a day, and the frequency of her chest PT is increased to 3-4 times a day. The duration of this change is dependent on her response to the change in antibiotics and chest physiotherapy. If she does well, this course is continued for a period of 2-4 weeks; however, if her condition worsens then she needs to have additional treatment and intensification of her therapy. Generally at this time it is necessary to start her on av antibiotics as well as continuing the intense frequency of her chest PT. This on occasion requires hospitalization, at least initially in the course of the illness, and if she is doing well she is often sent home to be treated at home by her mother who administers the IV medication. The type of medication varies according to the susceptibilities of the organisms found in her sputum. If, according to the sputum sample she requires 2 different antibiotics to be administered concurrently, she often has to remain in the hospital for the entire course of therapy. I have included a copy with this letter of our treatment of [petitioner] since November of 1988 when we assumed most of her care. This includes both changes in oral antibiotics as well as the initiation of IV therapy (whether in hospital or at home).

[Petitioner] has an infusaport for IV access which has been placed for the duration of its use under the surface of her skin. Routine maintenance of the infusaport requires that [petitioner's mother] flush the infusaport once a month with heparin. When [petitioner] is receiving antibiotics, this line must be flushed several times a day before and after the antibiotics.

> As I have mentioned, cystic fibrosis is a progressive pulmonary disorder in which pulmonary function deteriorates over time.. It is conceivable that sometime in the future [petitioner] would need to receive oxygen at home.. In general [petitioner] will require increased care as she gets older, as the damage to the lungs is progressive. Thus one would expect her to have an increased number of serious pulmonary infections in the future.

The record also includes another, more-recent (June, 1992), report from the petitioners' pulmonary specialist that describes in more detail the services provided to the petitioners by their mother.[3] This report is as follows:

> [Petitioner] has been in my care for her cystic fibrosis since early in her childhood. Her disease has progressed to the point that she now needs daily care which of the kind that is usually provided by health care professionals, and often requires even more complex care such as intravenous antibiotic therapy. Because her mother has acquired the specific technical and assessment skills needed to provide this care at home, [petitioner] has been able to avoid hospitalization except when the needs are unusually complex or intense.
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> The skilled nursing services which are currently being provided to [petitioner] by her mother include the following:
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> 1. Chest Physical Therapy. I have prescribed that [petitioner] receive this treatment once daily for prevention of lung infection, and up to four times daily for treatment of infection. This treatment requires specialized knowledge to administer, and is usually performed by a Respiratory Therapist. In Vermont, because of scarcity of professionals to provide the treatment at home, parents are taught the specific techniques needed and provide most of the routine care at home. When more than 2 treatments are needed per day, the time required becomes excessive and the services are purchased from the local home health agency of hospital. [Petitioner's] mother has learned the necessary techniques and provides the treatments under the supervision of [petitioner's] pediatrician and the Cystic Fibrosis Center professionals.
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> 2. Intravenous administration of antibiotics.

[Petitioner] requires continuous use of antibiotics to curtail and to treat her lung infections. Frequently there is no oral antibiotic which is effective against the bacteria causing a specific infection and the antibiotic must be administer intravenously. This treatment is prescribed by [petitioner's] pediatrician or the Cystic Fibrosis Center staff. For most patients, a 2 week period of hospitalization is needed and the intravenous antibiotics are administered by hospital nursing staff. [Petitioner's mother] has learned the necessary skills to administer the antibiotics at home, and many of the hospitalizations [petitioner] would otherwise have required have been avoided.

3. Observation and assessment of [petitioner's] condition. Cystic fibrosis leads to recurring lung infection, and the repeated infections result in chronic respiratory symptoms including cough and shortness of breath. The signs associated with a new infection may be subtle and will be missed by the untrained observer. If diagnosis is delayed, however, the infection will cause unnecessarily severe symptoms and will cause greater damage which will hasten [petitioner's] eventual death from her respiratory disease. [Petitioner's mother] has learned how to diagnose the infections at the earliest possible time, by assessment of the cough, the shortness of breath, and by examination of the chest and the sputum. These are assessments of the kind that are usually made by nurses or physicians, and her ability to diagnose infection in [petitioner] is greater than most health professionals because of her greater experience with [petitioner's] specific patterns.

[Petitioner's mother's] skills and care for [petitioner] have resulted in a marked decrease in total inpatient care, improvement in her capacity for normal physical and social development, and improvement in her general respiratory health. This care has not merely been in lieu of hospitalization but has greatly increased [petitioner's] quality of life.

It may be of interest that [petitioner] is currently undergoing one of her rare periods of in-hospital treatment and (sic) the Medical Center Hospital of Vermont. This has provided the opportunity to confirm the quality of care which [petitioner's mother] has been providing, and to update her skills in all the above areas.

At the hearing the petitioners' mother testified that

if she was not available to provide the above care and maintenance for her children, they would have to be hospitalized on a regular and recurring basis. The mother also stated that there are not trained people in her community who could provide the petitioners with the necessary care she now provides them. This testimony was uncontroverted.

ORDER

The Department's decisions are reversed.

REASONS

Medicaid Manual ə M 200(10) provides for Medicaid coverage under the following conditions:

> Disabled individuals 18 years of age or younger with respect to whom there has been a determination that:
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> - the individual requires a level of care provided in a hospital, skilled nursing facility, or intermediate care facility;
> - it is appropriate to provide such care for the individual outside such an institution;
> - the estimated amount which would be expended for medical assistance for the individual for such care outside an institution is not greater than the estimated amount which would otherwise be expended for medical assistance for the individual within an appropriate institution; and
> - the individual would be eligible for Medicaid if he or she were in a medical institution.
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> NOTE: this group is also known as the Katy Beckett coverage group. None of the income or resources of the parent(s) of a child included in this group is considered in determining his/her eligibility for Medicaid.

The above regulation essentially mirrors the federal statute. 42 U.S.C. ə 1396a(3).[4] In addition, a federal

statute, 42 U.S.C. э 1396d(f), defines "nursing facility services" as follows:

> . . . services which are or were required to be given an individual who needs or needed on a daily basis nursing care (provided directly by or requiring the supervision of nursing personnel) or other skilled rehabilitation services which as a practical matter can only be provided in a nursing facility on an inpatient basis.

In Vermont, the "Long Term Care Criteria" developed by the state Health Policy Council essentially reflects the above federal definition.[5]

Based on the uncontroverted medical evidence (supra) there is no question that the petitioners require skilled nursing care on a daily basis, and that their mother, through special training and dedication, is qualified to provide this care at home.[6] The evidence also compellingly demonstrates that "as a practical matter" the petitioners would require institutionalized nursing services were it not for the home care they receive from their mother.

The petitioners mother, on a daily basis, provides the petitioners with specialized chest physical therapy, oral and nebulized medication, and careful monitoring and assessment of their conditions. On a regular and frequent basis, she also administers IV antibiotics to combat the severe lung infections to which the petitioners are prone. As the petitioners' doctors point out (supra), monitoring the petitioners' condition requires vigilant and sensitive attention to "subtle" changes in their condition, something

at which the petitioners' mother, through training and experience, has become particularly adept. The medical evidence is clear and uncontroverted that the petitioners' ability to attend school, socialize, and avoid more-frequent hospitalizations is the direct result of their mother's "skills and care". The Department has offered no evidence that this level of care "as a practical matter" is available to the petitioners outside (or even inside) an institution. The petitioners' mother, who should know, testified that there is no home-based nursing service available in the community that could provide the petitioners with the same level of care. As noted above, this testimony is uncontroverted.

As a matter of law the Department is correct in requiring that children seeking eligibility for DCHC demonstrate that they require a level of care that is usually provided in a hospital or nursing facility. In this case, however, it appears that the Department, as a factual matter, has seriously overestimated the petitioners' level of functioning and underestimated the level of care required to maintain that level of functioning. For all the reasons discussed above, the Department's decisions are reversed.

FOOTNOTES

[1]The physician submitted an identical report for each petitioner. Only their names were different. Therefore, it is appropriate to use one report to refer to both petitioners.

[2]Id.

[3] Id.

[4] One difference is that the federal statutes have recently been amended to read "nursing facility" instead of "skilled nursing facility".

[5] Id.

[6] Because the petitioners mother is an "immediate relative", it does not appear that she would qualify for Medicaid payment as a "provider of services" to the petitioners. MM ə M 152.1(F).

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